

Commentary

People and technology must work together to solve the sharing problem

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This editorial is a good summary of the Wellcome Trust's publication¹ and as such suffers from the same two flaws. First, the Ipsos Mori survey² is correctly quoted but may suggest to the reader that there is broad, *unqualified* support from the public for research access to their records. In fact, elsewhere the same survey reports that even when the data is not sensitive only 35% of people think consent unimportant. Another possible interpretation is that two-thirds of people always think consent of some kind is required. This is mirrored in the opinions of the statutory body the Patient Information Advisory Group (PIAG – now the Ethics and Confidentiality Committee (ECC) accountable to the National Information Governance Board for Health and Social Care (NIGB)). PIAG/ECC–NIGB refer to the same survey,³ and state that:

Whilst consent can be implied for direct care purposes, based on the action of the patient, it is not usually reasonable to imply consent for secondary uses of data such as for research purposes.

Second, the paper has oversimplified the task of anonymising data and does not meet its own definition of 'anonymised' data. As the authors have described it, it is still possible to re-identify the patient. Simply storing longitudinal data for a patient that includes their visit dates will enable the patient to be identified by anyone who already knows a few of those visit dates. This is true regardless of whether the 'strong identifiers' are present or not. This weakness also spills over into the 'coded data' classification guidance. The risk of identifying patients when highly specific contextual data are provided (e.g. date of an operation) have been well explored within the pages of this journal.^{4,5,6}

Unfortunately there is no technology available to anonymise data for all possible users. What will work, however, is addressing the patient's fear of identification through a holistic approach to using their data; using established methods of pseudonymisation. Vetting researchers definitely helps here. But limiting

'illicit re-identification' from researcher, data or organisational failures would be a bigger advance.

REFERENCES

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- 3 PIAG response to NHS Connecting for Health consultation on additional uses of patient data. www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@ab/documents/digitalasset/dh_094695.pdf (accessed 30 September 2009).
- 4 Neame R. Privacy and health information: health cards offer a workable solution. *Informatics in Primary Care* 2008;16:263–70.
- 5 Navarro R. An ethical framework for sharing patient data without consent. *Informatics in Primary Care* 2008; 16:257–62.
- 6 de Lusignan S. Using routinely collected patient data with and without consent: trust and professionalism. *Informatics in Primary Care* 2008;16:251–4.

CONFLICTS OF INTEREST

Sapior Ltd provides information technology applications to enable ethical data sharing.

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